## Opening Statement by the Honorable Brad Ellsworth Subcommittee on Disability Assistance & Memorial Affairs April 24, 2007

Mr. Chairman, thank you for the opportunity to testify on behalf of Honey Sue and the Nesler Family of New Harmony, Indiana. Today, I will read the heartfelt testimony prepared by Honey Sue's father, Ron Nesler. Mr. Nesler has detailed his family's daily struggle to provide care for Honey Sue who has a complicated neurological disorder rooted in Spina Bifida. Honey Sue's condition is the result of her birth father's exposure to Agent Orange while he served three tours of duty as a Marine Rifleman in the Vietnam War. It is my hope that Honey Sue and the estimated 200 children with Level III Spina Bifida as caused by a parent's exposure to Agent Orange receive the same full health care coverage as the 100% Service Connected military veterans.

# Statement of Ron Nesler, Father Testimony before the Subcommittee on Disability Assistance & Memorial Affairs

I am Honey Sue Newby's stepfather, Ron Nesler. My wife Suzanne Nesler is Honey Sue's birth mother. Suzanne and I are Honey Sue's court appointed guardians and full time care givers. Honey Sue is a beautiful 36 year-old child with complicated neurological disorders rooted in Spina Bifida. She requires around the clock aid and attendance care and extensive medical care. The VA concedes that Honey Sue's condition is the result of her birth father's exposure to Agent Orange while serving three separate 13 month tours in combat as a Marine Rifleman in the Vietnam War.

Honey Sue is very bright, happy, and gregarious. But emotionally she operates at about the 10 to 12 year-old level and always will. She is the greatest joy in our lives. We are grateful for the opportunity to care for her.

Honey Sue's birth father was a 3 tour combat Marine Rifleman in the Vietnam War.

Honey Sue is diagnosed with Spina Bifida as the root cause of her neurological problems.

When the VA Spina Bifida Program was started, her mother and I applied for

VA compensation for Honey Sue. The VA acknowledges about 1200 children of Vietnam

Vets as having some degree of disability caused by Spina Bifida as related to a birth parents exposure to A/O in Vietnam. The children are rated as Level I through Level III according to their degree of disability with Level III being the greatest degree of disability.

Honey Sue is one of only about 200 of the 1200 children rated as Level III. We are told by the VA that this is the approximate equivalent of a 100% Service Connected Disability rating for a military veteran. All 1200 children are paid monthly monetary compensation by the VA. The amount of the monthly compensation is based on their degree of disability. As a Level III totally disabled A/O Spina Bifida child, Honey Sue receives about \$1,500 per month in VA compensation.

A 100% Service Connected (SC) military veteran whose situation seems to mirror Honey Sue's situation exactly as to cause and result receives about \$2,500 per month. Honey Sue and the roughly 200 other Level III children receive only scraps of very difficult to access health care coverage from the VA. And these bits and pieces of health care specifically exclude Honey Sue's greatest need which is aid and attendance care. The 100% SC military veteran receives full medical care including aid and attendance when needed.

Our position is that since the Congress created the law recognizing the 200 Level III children as totally disabled as a direct result of a birth parents military service, Congress should ensure full health care benefits including aid and attendance care for these 200 children.

Our greatest concern is who will care for and protect Honey Sue when her mother and I are gone? We feel the Congress owes a debt to provide full health care for the Level III children including aid and attendance care. These children should receive the same care as is provided for a 100% service connected disabled veteran. No more and no less.

Both Honey Sue and the 100% SC disabled military veteran are conceded to be totally disabled as a result of military service. They should be treated the same.

While the VA does provide some level of health care to the totally disabled Level III A/O children it is very difficult to access. The first hurdle is to find a doctor who is willing to write a letter to the VA prior to treatment stating that the necessary medical care is needed as a direct result of Spina Bifida. After the letter is sent we typically have to wait several months to get approval for the VA payment. Then even if the care is finally approved the same daunting process is required the next time the same condition requires treatment. This is a bureaucratic nightmare.

This obviously does not work in the emergencies which frequently arise in caring for Honey Sue. The best way we have found to deal with this is to pay out of pocket for Honey Sue's care and then battle it out with the VA after the fact for reimbursement. Or, we depend on welfare or private charities to provide the needed care. Honey Sue has received more and better health care through the years as charity from the Shriners and the Elks than she has as compensation through the VA. We feel that this is a national shame.

We wonder what happens to Level III children like Honey Sue whose parents do not have the money to pay up front and then fight a battle for repayment with the VA. What if the parents do not have the verbal or paper work skills to fight the battles with the VA or they do not know how to access care from private charities? Without strong advocates, these children will not receive the necessary care. We also wonder what happens when we finally face a need for care for Honey Sue that we are unable to fill "By Hook or By Crook" through welfare or private charity as we are presently forced to do. We know that day will likely eventually come. The fact we are becoming elderly and less able makes it even more likely and frightening.

To exacerbate our situation, the local Social Security Administration (SSA) office is at this very moment engaged in forcing us to apply for Medicare benefits for Honey Sue that even they admit it may cost her the loss of a significant amount of her Medicaid coverage and leave her with even less health care protection than she currently has. We are told that this is "the law" and we must comply or they will cancel all of Honey Sue's SSI and Medicaid benefits as a penalty for noncompliance. SSA says we have no recourse even though they

agree that to do this is obviously against Honey Sue's best interests. I am worried. Honey Sue's mother is sick and distraught over this threat to Honey Sue' well being.

This is not how things should be. We do not think it is how the Congress intended things to be when the VA Spina Bifida Program was created. The government has admitted that the total disability of these 200 Level III kids is the result of military service. They should not have to fight like dogs competing for scraps to get needed medical care. It should be automatic just like the 100% service connected disabled veteran who has the same situation as Honey Sue's.

We include with this letter a legislative Memorial passed by the state legislature of the State of New Mexico. The memorial was sponsored by State Representative Nate Cote in the New Mexico House of Representatives and by Senator Leonard Lee Rawson in the New Mexico State Senate. It was supported by Secretary John M. Garcia the Secretary of New Mexico Department Veteran Affairs and backed by the national office of the Vietnam Veterans of America (VVA). The intent of the Memorial is to recognize the plight of the A/O Spina Bifida children and their families and to urge Congress to finally pay its debt to these children who are victims of friendly fire from the Vietnam war by providing them full health care coverage and full aid and attendance care through the VA Spina Bifida Program. We have included the copy of the New Mexico state legislative Memorial to demonstrate that others besides our family recognize the injustice of the treatment dished out to the Level III children.

The people to whom I am very grateful for being involved in passing this New Mexico state legislative memorial for Honey Sue are:

1. Rep Nate Cote originally sponsored the memorial in the New Mexico House of Representatives. Rep. Cote's phone number is (505) 202-1872 and his email is NCote@Zianet.com.

- 2. Senator Leonard Lee Rawson sponsored the memorial in the New Mexico State Senate. Senator Rawson's phone number is (505) 647-3568 and his email is <a href="mailto:LRAWSON@Rawson-inc.com">LRAWSON@Rawson-inc.com</a>.
- 3. Secretary John M. Garcia, Secretary of the Department of Veteran Affairs for the state of New Mexico supported the memorial for Honey Sue and is a true friend of veterans. His phone number is (505) 469-4986 and his email address is John M. Garcia @state.nm.us.
- 4. Lou Helwig is an assistant to Secretary John M. Garcia in the New Mexico Department of Veteran Affairs. He is very knowledgeable of Honey Sue's situation and testified in support of the memorial in the New Mexico state legislature. Mr Helwig's phone number is (505) 827-6312 and his email is lou.helwig@state.nm.us.
- 5. Rick Weidman (<u>RWeidman@vva.org</u>), Sharon Hodge (<u>SHodge@vva.org</u>), and John Rowan (<u>jrowan@vva.org</u>) of the Vietnam Veterans of America were all supportive of the memorial for Honey Sue they may be reached by phone at (301) 585-4000.
- 6. Richard Curry is a writer for the "Veteran" the magazine of the Vietnam Veterans of America. He has contacted our family about doing a story in the near future about the many challenges facing Honey Sue as a Level III Agent Orange Spina Bifida child. Mr. Currey's email address is richcurr54@yahoo.com.

The financial cost of paying the debt to these children would be very small due to the fact that there are only about 200 of them. Ironically, we feel the reason that this sad situation is allowed to persist is exactly because only 200 such Level III children exist.

We ask that Congress create legislation providing full health care coverage including aid and attendance care for the fewer than 200 Level III Agent Orange Spina Bifida children currently acknowledged by the VA. Thank you for your interest.

#### HOUSE JOINT MEMORIAL 5

48TH LEGISLATURE - STATE OF NEW MEXICO - FIRST SESSION, 2007

### INTRODUCED BY

### Nathan P. Cote

### A JOINT MEMORIAL

URGING CONGRESS TO FULLY FUND MEDICAL CARE AND AID AND ATTENDANT
CARE SERVICES FOR HONEY SUE NEWBY AND THE OTHER LEVEL THREE SPINA
BIFIDA CHILDREN OF PARENTS WHO SERVED IN VIETNAM AND WHO ARE
TOTALLY DISABLED.

WHEREAS, the federal department of veterans affairs acknowledges that one thousand two hundred children of Vietnam war veterans have some degree of disability resulting from their birth parents' exposure to agent orange during military service in the Vietnam war; and

WHEREAS, approximately two hundred of these children of war veterans are designated as level three spina bifida children, who are considered to be totally disabled; and

WHEREAS, these children, designated as totally disabled as a result of their birth parents' exposure to agent orange during military service in Vietnam, are in a situation that is indistinguishable from that of any one hundred percent service-connected disabled veteran who is totally disabled as the result of military service; and

WHEREAS, these two hundred level three spina bifida children of Vietnam war veterans are not treated equally with the disabled military veterans as regards compensatory medical care and aid and attendant care; and

WHEREAS, the financial cost for families of these children can be crippling, and many proud American military veterans and their families must depend on welfare or charity to provide the vital medical care and attendant care their children need; and

WHEREAS, at least one of these children, Honey Sue Newby, whose birth father served three tours as a marine infantryman in Vietnam, resides in New Mexico; and

WHEREAS, the legislature seeks to honor and encourage fair treatment of all persons who have made personal sacrifices in the military defense of our nation;

NOW, THEREFORE, BE IT RESOLVED BY THE LEGISLATURE OF THE STATE OF NEW MEXICO that it urge the United States congress to provide full medical care and attendant care to Honey Sue Newby and the other level three spina bifida children who are totally disabled as a result of their birth parents' military service in Vietnam; and

BE IT FURTHER RESOLVED that the New Mexico congressional delegation be requested to work vigorously for adequate funding to provide full medical care and aid and attendant care to all level three spina bifida children who are totally disabled because of the effects of agent orange used in Vietnam; and

BE IT FURTHER RESOLVED that copies of this memorial be transmitted to each member of the congressional delegation, the chief clerks of the United States house of representatives and the United States senate and the United States department of veterans affairs.